



## **Clinical Practice Guidelines:**

### Developmental Screening, Assessment and Referral for Patients up to 30 Months of Age

(Developed in partnership by the Medicaid Managed Care Organizations, Department of Health and Health Care Authority)

### DEVELOPMENTAL SCREENING, ASSESSMENT AND REFERRAL FOR CHILDREN

#### GOAL

To outline methods of identifying children up to 30 months of age with possible developmental delays and provide guidance around referral for appropriate interventions.

# SCREENING TOOLS AND INTERVENTIONS FOR COMMON DEVELOPMENTAL DISORDERS SEEN IN PRIMARY CARE

#### **Developmental Delays in Children**

- As many as one in four children through the age of five years of age are at risk for a developmental delay or disability. Early identification allows earlier intervention, leading to more effective and less costly treatment during the preschool years, reducing the need for expensive special education services in later childhood. Developmental delays affect between 10 and 13 percent of U.S. children under the age of three years, yet nationally only 2 to 3 percent of children in this age group receive Early Intervention (EI) services. In Washington State, 2.2% of infants and children birth to three years old were served by Early Intervention during July 1, 2012 June 30, 2013.
- There is strong evidence that infants and toddlers with developmental concerns are at elevated risk for learning and cognitive disabilities, speech and language difficulties, and behavioral problems at school age. The impact can extend well beyond the childhood years; children with such concerns or delays are more likely to be in poor health, have low educational attainment, and have lower income as adults than their peers who do not face such challenges. However, evidence shows that the timely receipt of early intervention services can be effective in improving developmental outcomes.
- The short time it takes to conduct a developmental and behavioral screen can change the trajectory of a child's life forever. By incorporating a system of regular developmental and behavioral screening, you can play an important role in making sure all children thrive.

### Screening and Follow Up for Developmental Delays and Autism in Children

- The American Academy of Pediatrics recommends that:
  - Developmental surveillance is performed at every well-child preventive care visit, with any concerns followed up with administration of a standardized developmental screening tool.
  - A standardized developmental screening tool should be administered at the 9, 18, and 24/30 month visits or any time a parent or provider is concerned.<sup>1</sup>
  - An autism screen is administered at 18 and 24 months (see section below on Autism).

<sup>1</sup>This schedule is based on the Bright Futures<sup>™</sup>/American Academy of Pediatrics periodicity schedule of recommendations for Preventive Pediatric Health Care at: <u>http://www.aap.org/en-us/professional-</u> <u>resources/practice-support/Periodicity/Periodicity%20Schedule\_FINAL.pdf</u>. Recommended Screening Tools (Cont).

- There are several reliable and validated screening tools for identifying developmental concerns in children. We will focus on a few that are frequently used by primary care providers. A longer list is available at the link at the end of this section:
  - Ages & Stages Questionnaires<sup>®</sup>, *Third Edition* (ASQ-3): A developmental screening system made up of 21 age-specific questionnaires completed by parents or primary caregivers of young children in as little as 10 to 15 minutes. The questionnaires can identify children who are in need of further assessment, including determining whether they are eligible for early intervention or early childhood special education services. The ASQ-3 is available in paper or electronic versions.
    - The ASQ is available in several languages, which can be found at: <u>http://agesandstages.com</u>.
    - For additional information or to access the screening tools, go to: <u>http://agesandstages.com</u>.
    - Ages and Stages also offers a screening tool for assessing social and emotional wellness. It is important to note that the ASQ:SE focuses on the one domain of development and does not meet specifications for global developmental screening tools. To learn more about Ages & Stages Questionnaires<sup>®</sup>, Social-Emotional (ASQ:SE-2) go to: http://agesandstages.com/asq-products/asqse.
  - Parent's Evaluation of Development Status (PEDS) and PEDS: Developmental Milestones (PEDS: DM): A single questionnaire containing the same 10 open-ended questions for all ages to elicit and address parent's concerns. PEDS: DM provides 6-8 milestones-type items per well visit. For additional information or to access the PEDS screening tools, go to: <u>http://www.pedstest.com/default.aspx</u>. There is also an online version of the PEDS screening tool. You can learn more about this

There is also an online version of the PEDS screening tool. You can learn more about this option at: <u>http://www.forepath.org/custom.php</u>.

• To learn more about other validated screening tools for developmental delays, go to: <u>https://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive</u>.

# Scoring and intervention guidelines for using the ASQ-3<sup>™</sup> with Parents and Children

• The questions on the ASQ-3<sup>™</sup> address five developmental areas (Communication, Gross Motor, Fine Motor, Problem Solving, and Personal-Social). After completion by the parent of the questionnaire, the provider will enter the total scores for each developmental area on an Information Summary sheet, comparing the child's score in each area to a cutoff score.

# ASQ-3<sup>™</sup> Scores and Proposed Treatment Actions for Potential Developmental Delays in Children

Find further information for Ages & Stages Questionnaires<sup>®</sup>, Third Edition (ASQ-3) at: <u>http://agesandstages.com/products-services/asq3</u>

- All "at risk" screenings (or additional concerns from the provider, parent or caregiver, regardless of the results) should be immediately addressed. Intervention need not wait for a full evaluation or a definitive diagnosis.
- Suggest activities parents/caregivers can try at home to stimulate development. Tips and activity
  suggestions are included with the ASQ3 (on accompanying disc) and can be printed and given to
  parents/caregivers. Additionally, tips and activities can be found at 'Learn the Signs. Act Early' CDC: <u>Go</u>
  <u>Out and Play! Kit</u>.
- Refer to the appropriate early intervention program for further evaluation of development and

eligibility determination for services. A specific diagnosis is not needed for an early intervention evaluation or services. Have your staff help to facilitate any referral, such as assisting with appointment scheduling, transportation, language or physical needs. Ask the program to contact the parent to ease their burden.

- For a child birth to three years of age, refer to the Family Resources Coordinator for the early intervention program (Early Support for Infants and Toddlers in Washington State); for a child three years of age or more refer to the special education preschool program in the district where the family lives. To locate services in their area you can go to <a href="http://parenthelp123.org/child-development/child-development-screening-public">http://parenthelp123.org/child-development/child-development-screening-public</a> or call 1-800-322-2588.
- Families may self-refer. In order to better coordinate care and facilitate the referral, fax a referral form with specific information to the early intervention program or school district with the screening results and ask for an evaluation (click <u>here for a Birth to Three Program (ESIT)</u> referral form).
- Depending on findings of further evaluation, facilitate a medical evaluation for developmental delay/variance to identify a specific developmental disability and appropriate treatment plan. Provide referral to an appropriate medical sub-specialist or multi-disciplinary team for a comprehensive medical evaluation. Referrals may include a developmental pediatrician, neurologist, psychologist, geneticist, physical therapist, occupational therapist, speech and language pathologist, audiologist or other provider.

## **Talking to Families and Caregivers**

**Talking to families after an "at risk" screening result**: The following suggestions can help you and the parents/caregivers work together for the best outcome for the child. There is a parent conference sheet on the disc with the ASQ 3 that can help direct and document a parent 'conference'.

- When talking to families, it is best to use the language used at home. Use a medical interpreter as needed.
- Start off by pointing out something positive. Name a skill or behavior the child is doing well and note their progress.
- If you are concerned about a child's development, point out the specific behavior(s) the child is struggling with and ask if they observe the same behavior(s) at home. It is okay to say, "I may be overly concerned, but I just want to make sure." Engage the family in a discussion. Give them time to listen, reflect, and provide input.
- Suggest activities that families can practice with their child to help in development.
- Stress that a screening does NOT provide a diagnosis. An "at risk" screen simply means the child should be evaluated more thoroughly. Even if you and/or the parent are not concerned, an "at risk" result indicates further evaluation is needed. Standardized screening tools detect many delays before delays are overtly apparent.
- Indicate that you will refer them to the appropriate early intervention program for further evaluation. Explain that if there is a delay, early intervention is the best approach. But parents do not *have to* enroll a child in early intervention if they are determined eligible. For more information on early intervention services, contact Early Supports for Infants and Toddlers at <a href="https://del.wa.gov/providers-educators/early-support-infants-and-toddlers-esit">https://del.wa.gov/providers-educators/early-support-infants-and-toddlers-esit</a> or call 360-725-3514. Information on initial evaluation for special education in Washington State can be found at <a href="http://www.kl2.wa.us/SpecialEd/Families/Evaluations.aspx">http://www.kl2.wa.us/SpecialEd/Families/Evaluations.aspx</a>).
- Work together to create a list of questions to ask the specialist or early intervention service or early childhood special education provider as a result of the screen.

- Use the information in the *Birth to 5: Watch Me Thrive!* Primary Care Provider's Guide for Developmental and Behavioral Screening at <u>http://www.acf.hhs.gov/programs/ecd/watch-me-thrive</u> to answer the family's questions.
- Remind the family that you are their partner on their child's developmental journey.

### Talking to families after a "low risk/monitor" or "no risk" screening result:

- Discuss the results with the family and remind them that monitoring a child's development should be
  ongoing in the home, child care settings, and elsewhere. Families can complete free online screenings
  using the ASQ to track their child's behavior between visits. In addition to the screening tool, they will
  also receive activities to do with their child to support developmental growth. Families can access the
  free screener at: <a href="http://parenthelp123.org/child-development/child-development-screening-public">http://parenthelp123.org/child-development/child-development-screening-public</a>.
- Give them materials that describe their child's next developmental level. Be sure they are enrolled to receive the Washington State Child Profile Health Information Mailings, which contain a wealth of developmental and health information (<u>Link to sign up</u>). The Learn the Signs, Act Early 'Milestones Moments' booklets (<u>English</u> and <u>Spanish</u> versions) and <u>website</u> can also help serve this purpose.
- Use the screening results to talk about the child's strengths and challenges. The Ages & Stages
  Questionnaires<sup>®</sup>, Third Edition (ASQ-3) manual offers ideas for activities in Appendix F that families
  can do with their child to help in development.
- If a child has a "low risk" or "no risk" screen *and you still have concerns*, discuss your concerns with the family. Depending on your level of concern, indicate a need to administer another developmental screen in the near future or to refer the child to a specialist who can do a more thorough evaluation.
- Connect the family with early learning programs or parenting programs in their community that can help support the child's development. 'Help Me Grow Washington' at WithinReach can connect the family to a wide variety of services in their area. Families can find nearby programs and get assistance by calling the Family Health Hotline at 1-800-322-2588 or on the web at <u>www.parenthelp123.org</u>. Adapted from the *Birth To 5: Watch Me Thrive!* Primary Care Provider's Guide for Developmental and Behavioral Screening at <u>http://www.acf.hhs.gov/programs/ecd/watch-me-thrive</u>.

## Ongoing Monitoring and Surveillance of Developmental Delays in Children

- Maintain a Developmental History: Along with screening for developmental delays using a validated screening tool at appropriate well-child visits, it is important to continue to ask parents/caregivers at every visit if they notice any changes in their child's development since the last visit. Documenting the results, along with other history can assist providers in identifying developmental concerns that warrant further investigation.
- Set up a system to track if families are connecting with referral to services and the outcome of that referral.

### **Resources:**

- Child Profile Health Information Materials (add the information and links)
- Birth to 5: Watch Me Thrive! A Compendium of Screening Measures for Young Children from the US
  Department of Health and Human Services: <u>https://www.acf.hhs.gov/ecd/child-healthdevelopment/watch-me-thrive</u>
- Developmental Health Information for Healthcare Providers: <u>http://www.cdc.gov/ncbddd/actearly/hcp/index.html</u>
- Developmental Screening Introduction provides .5 hours of Continuing Medical Education for Healthcare Providers this 30 minute interactive module is available to primary care providers by contacting the Department of Health for a login. For access email: <u>WHIN@doh.wa.gov</u> with subject

line: "Developmental Screening CME".

- Oregon Health Sciences is the NCQA measure steward The website for their specifications is: <u>http://www.oregon-pip.org/focus/DevScreening.html</u>
- Certification of Comparability of Pediatric Coverage Offered by Qualified Health Plans and Annual enrollment reports: <u>https://www.medicaid.gov/chip/reports-and-evaluations/index.html</u>
- Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening: http://pediatrics.aappublications.org/content/118/1/405.full
- WithinReach WA (Resources for Providers and Families): <u>http://www.withinreachwa.org/what-we-do/healthy-families/child-development</u>

# Autism Spectrum Disorder (ASD)

- Autism is one of the most common developmental disabilities. According the Centers for Disease Control and Prevention 2014 prevalence data, 1 out of 68 US children, age 8, will have an Autism Spectrum Disorder (ASD). This is an increase of 30% since two years ago, when it was estimated that 1 in 88 children will be identified with ASD. ASD is almost 5 times more common in boys (1 in 54) than in girls (1 in 252). ASD affects people of every race, ethnic group, and socioeconomic background.
- Autism spectrum disorder (ASD) and autism are both general terms for a group of complex neurodevelopment disorders, characterized in varying degrees by difficulties in social interaction, verbal and nonverbal communication, and restricted, repetitive behavior. The May 2013 publication of the <u>DSM-5 diagnostic manual</u> merged all autism spectrum disorders into one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome.

Source: Autism Speaks: http://www.autismspeaks.org/what-autism

## Screening and Follow-up for Autism in Children

Research has found that ASD can sometimes be detected at 18 months or younger. By age 2 to 2½, a diagnosis by an experienced professional can be considered very reliable. However, many children do not receive a final diagnosis until they are much older. This later diagnosis means that many children with ASD miss out on early interventions that may improve their outcomes. It is important to screen early to identify any potential issues and start treatment as soon as possible. The American Academy of Pediatrics recommends every child be screened for autism at ages 18 months and 24 months. Additional screening may be indicated if a child demonstrates concerning signs consistent with ASD or has siblings or other family members with ASD. The following screening tools are available for screening for ASD:

- Parent-Completed Screening:
  - M-CHAT-R/F: The newly revised M-CHAT–R/F<sup>™</sup> (Modified Checklist for Autism in Toddlers, Revised with Follow-Up) has been shown to identify autism at an early age (two years younger than the current national mean age of diagnosis). Almost all children with a positive two-stage M-CHAT-R/F screening had autism spectrum disorder or other delays; only 5.4% were judged to be typically developing. It is a validated autism screening tool for children 16-30 months old. For additional information or to access the M-CHAT screening tool, go to: <u>http://www2.gsu.edu/~psydlr/M-CHAT/Official M-CHAT Website.html</u>.
  - Ages and Stages Questionnaire Social Emotional (ASQ-SE): A screening tool for socialemotional development that can be filled out by parents or providers and is designed for children from 6 to 60 months of age. It does not require a follow-up interview. At present there are no published studies examining the use of the ASQ-SE as a screening tool for ASD,

but promising research on the ASQ and ASQ-SE is under way, so watch for future information.

- Observer-Administered Screening:
  - Screening Tool for Autism in Toddlers (STAT<sup>™</sup>): Designed for a wide-range of professionals working with young children in assessment or intervention settings, the STAT<sup>™</sup> is a *second-level screening tool for use in referral settings* to identify children who are at risk for autism within samples of children for whom there are developmental concerns. The STAT is a play-based assessment that can be administered in about 20 minutes. It contains 12 items assessing the areas of play, communication, and imitation. It is validated for children between 24 and 36 months of age, and preliminary data supports its use in children as young as 14 months of age. For additional information or to learn how to receive training to administer the STAT<sup>™</sup>, go to: http://depts.washington.edu/readilab/asap.html.
  - To learn more about other validated screening and diagnostic tools for Autism Spectrum Disorder, go to: <u>http://www.cdc.gov/ncbddd/autism/hcp-screening.html</u>.

SCORE	LEVEL OF RISK	PROPOSED RECOMMENDATION
0-2	Low Risk	If child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.
3-7	Medium Risk	<ul> <li>Administer the Follow-Up Interview (second stage of M-CHAT-R/F) to get additional information about at-risk responses.</li> <li>If score on Follow-Up Interview is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.</li> <li>Action required: If M-CHAT-R/F score remains at 2 or higher, the child has screened positive, refer child for both a diagnostic evaluation and eligibility evaluation for early intervention.</li> </ul>
8-20	High Risk	It is acceptable to bypass the Follow-Up Interview and refer immediately for both diagnostic evaluation and eligibility evaluation for early intervention.

## M-CHAT- R/F Scoring Guidelines

# **Treatment Guidelines for Autism Spectrum Disorder**

- There is currently no known cure for ASD. Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement. The ideal treatment plan coordinates therapies and interventions that are specialized to meet the needs of individual children. Participation in ASD-specialized intervention at young ages has been associated with substantial improvements in cognitive and language skills in some individuals.
  - Educational/behavioral interventions: Therapists use highly structured and intensive skilloriented training sessions, such as Applied Behavioral Analysis (ABA), to help children develop social, language, and adaptive behavior skills. Speech-language therapy is useful for improving children's verbal and nonverbal language skills. Occupational Therapy is used to promote the development of fine motor skills, play, and adaptive behavior skills such as feeding. Family counseling for the parents and siblings of children with an ASD often helps families cope with the particular challenges of living with a child with an ASD.
  - **Medications:** Doctors may prescribe medications for treatment of specific autism-related symptoms, such as anxiety, depression, or obsessive-compulsive disorder. Antipsychotic

medications are used to treat severe behavioral problems. Seizures can be treated with one or more anticonvulsant drugs. Medication used to treat people with attention deficit disorder can be used effectively to help decrease impulsivity and hyperactivity.

 Other therapies: There are a multitude of "complementary and alternative" treatments available, but the effectiveness of these treatments has not been demonstrated by scientific studies. Parents should use caution before adopting any unproven treatments. Although dietary interventions have been helpful in some children, parents should be careful that their child's nutritional status is carefully followed.

## **Resources:**

- Center for Disease Control and Prevention (CDC) Autism Spectrum Disorder: Screening and Diagnosis from Health Care Providers <u>http://www.cdc.gov/ncbddd/autism/hcp-screening.html</u>
- Autism Speaks: http://www.autismspeaks.org/what-autism

## **EDUCATION RESOURCES**

Patient and family education about developmental growth can be very useful. Helpful websites for information and resources include:

- Child Development/Developmental Screening
  - Child Profile Health Information Mailings and Emails <u>http://www.doh.wa.gov/YouandYourFamily/Immunization/ChildProfileHealthPromotion/Child</u> <u>ProfileSignUp</u>
  - WithinReach WA <u>http://www.withinreachwa.org/what-we-do/healthy-families/child-development</u>
  - Help Me Grow Washington/Parent Help 123
     <a href="https://resources.parenthelp123.org/services/developmental-screening">https://resources.parenthelp123.org/services/developmental-screening</a>
  - o Developmental Screening Fact Sheet from the Centers for Disease Control and Prevention
  - o <a href="https://www.cdc.gov/ncbddd/actearly/pdf/checklists/all\_checklists.pdf">https://www.cdc.gov/ncbddd/actearly/pdf/checklists/all\_checklists.pdf</a>
  - Learn the Signs. Act Early. (A guide for parents) <u>https://wwwn.cdc.gov/pubs/CDCInfoOnDemand.aspx?ProgramID</u>=2
  - Birth to 5: Watch Me Thrive! Families <u>http://www.acf.hhs.gov/programs/ecd/watch-me-thrive/families</u>
- Social Emotional Health
  - Mental Health Surveillance Among Children United States, 2005-2011: <u>https://www.cdc.gov/mmwr/preview/mmwrhtml/su6202a1.htm?s\_cid=su6202a1\_w</u>
  - OSPI Social Emotional Learning Workgroup recommendations to the Washington Legislature, 2016: <u>http://www.k12.wa.us/Workgroups/SELB-Meetings/SELBWorkgroup2016Report.pdf</u>
  - Family Tools from the Center on the Social and Emotional Foundations for Early Learning <u>http://csefel.vanderbilt.edu/resources/family.html</u>

#### • Autism

- Autism Spectrum Disorders Signs and Symptoms. Centers for Disease Control and Prevention <u>http://www.cdc.gov/ncbddd/autism/signs.html</u>
- Autism Guidebook for Washington State: A Resource for Individuals, Families, and Professionals <u>http://here.doh.wa.gov/materials/autism-guidebook</u>
- Autism and Medication: Safe and Careful Use: Toolkit to help families work with providers to insure prescribed medication is taken safely and effectively <u>http://www.autismspeaks.org/science/find-resources-programs/autism-treatment-</u> <u>network/tools-you-can-use/atn-air-p-autism-medication-safe-careful-use</u>

### REFERENCES

PolicyLab Releases Data from Translating Evidence-based Developmental Screening (TEDS) Study: <u>https://helpmegrownational.org/resources/policylab-releases-data-from-translating-evidence-based-</u> <u>developmental-screening-teds-study</u>

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Autism Speaks: <a href="http://www.autismspeaks.org/what-autism">http://www.autismspeaks.org/what-autism</a>